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Cancer Disparities for People With Disabilities: Bridging the Gap

Dikaïos Sakellariou, PhD, and Elena S. Rotarou, PhD

There are approximately one billion people with disabilities globally. Despite the fact that disability affects roughly 15% of the global population, it is often overlooked both in health policy and in research on health access.¹ Therefore, not only do people with disabilities experience disparities in health access and outcomes, but their needs and experiences also remain invisible.² In this issue of *JNCCN*, Iezzoni et al³ draw attention to this population, exploring the association between disability and cancer in the United States. This is one of the few studies that focus specifically on examining incidence of cancer among people with disabilities, a particularly important yet underexplored issue. Although there is a growing body of evidence on disparities in cancer service utilization for people with disabilities, predominantly screening and diagnostic services, limited information is available on cancer incidence.

People with disabilities are among the most disadvantaged population groups; they often experience structural disadvantage in the form of increased poverty levels, lower literacy levels, and higher rates of unemployment or informal employment compared with the general population.⁴ Such structural disadvantage intersects with “ableism,” which is discrimination against people with disabilities and the expectation that all bodies can or ought to conform to an idealised nondisabled norm. This intersection leads to compromised access to healthcare services and to living conditions linked to poorer health. Direct and indirect discrimination against people with disabilities can lead to increased barriers to accessing healthcare and reduced use of cancer services.

An increasing body of evidence indicates lower participation in cancer screening for people with disabilities, due to a number of physical, institutional, financial, and attitudinal barriers. Such barriers include inaccessible healthcare facilities and/or equipment, lack of social support, financial constraints, past negative experiences with healthcare professionals, discomfort, inadequate information, lack of or inappropriate transport, and inadequate training of healthcare professionals, among other factors.^{5,6} Similar sets of barriers and patterns of disparities are observed globally across different healthcare systems; evidence suggests that people with disabilities experience worse access to cancer screening not only in the United States⁷ but also across the world, including even in countries with universal health coverage and public healthcare that is free at the point of delivery, such as the United Kingdom.⁸

Various studies also underline the existence of disparities in cancer treatment and substandard experiences of service provision.^{9,10} Behind the statistics of cancer screening underuse are human stories: men and women with disabilities who—worried about new, unfamiliar symptoms—try to get screened but whom doctors are reluctant to refer, possibly due to diagnostic overshadowing; wheelchair users being asked to stand up; and healthcare professionals not exploring ways to adapt processes to make them disability-inclusive, exemplifying a general lack of disability inclusiveness in the provision of healthcare services.^{10,11}



See page 1031 for related article.

The study by lezzoni et al³ provides novel insights and much-needed knowledge about the associations between disability and cancer incidence in the United States. The researchers used a nationally representative survey—the 2010–2017 National Health Interview Surveys—to investigate the relationship between disability and four common types of cancer: colorectal, prostate, ovarian, and non-Hodgkin's lymphoma. The study included people who had movement difficulties or complex activity limitations that predated the cancer diagnosis. In line with existing evidence, lezzoni et al³ found that people with disabilities were older, had lower education levels, were generally poorer, had a higher body mass index, and were more likely to have a smoking history. Importantly, study findings showed that people with preexisting disabilities had significantly higher rates of cancer and that they were older when initially diagnosed compared with people without disability. Multivariable regressions, accounting for sociodemographic and risk factor characteristics, showed that preexisting disability—disability that predated the cancer diagnosis and was not a result of cancer—was strongly associated with colorectal and prostate cancers, and non-Hodgkin's lymphoma.

The study findings may be alarming, but they are also unsurprising considering the barriers that people with disabilities experience when seeking screening services. The study should serve as a call to action for policymakers, healthcare managers, and clinicians. Even when people with disabilities do access these services, diagnostic overshadowing, which is the erroneous attribution of new symptoms to a patient's preexisting disability, may delay cancer diagnosis. The study underlines the need to ensure the provision of appropriate screening and comprehensive exploration of all new signs and symptoms for people with disabilities, in order to ensure timely diagnosis.

The evidence provided by lezzoni et al³ adds real urgency to the need to work toward reducing cancer disparities for people with disabilities, through taking a twinforked approach, focusing both on the provision of disability-inclusive healthcare, including cancer services, and on the exploration and reduction of increased cancer incidence. It is important to disaggregate existing cancer data by disability in order to understand the mechanisms associated with cancer disparities for people with disabilities. Although a wealth of cancer-related evidence is available, databases often do not include information on disability, making it very difficult to measure disability-based disparities. The invisibility of this population in cancer statistics might contribute to their needs being overlooked. Ensuring that all cancer data include the Washington Group questions,¹² which aim to identify people with disabilities in datasets, can provide visibility for this population in cancer statistics. This would allow an in-depth exploration of the interactions between factors such as age, sex, disability, and illness and environmental influences, including geographic location, government policies, and the natural and built environment, in order to better understand disparities in cancer screening, incidence, stage at diagnosis, treatment, and outcomes for people with disabilities.

Making disability-disaggregated data available is one step toward bridging cancer disparities for people with disabilities. This needs to be coupled with an effort to make all health services disability-inclusive, because the mere existence of services does not guarantee accessibility and usability. To ensure that cancer services are disability-inclusive and ultimately accessible, they must be available, affordable, relevant, appropriate, and acceptable to service users with disabilities. All of these dimensions of accessibility are equally important, and they interact with each other to facilitate or inhibit access to services. Although the Americans with Disabilities Act in the United States and similar pieces of legislation across the world, including the United Nations Convention on the Rights of Persons with Disabilities, explicitly prohibit disability-based discrimination in healthcare, people with disabilities face



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several barriers when they seek to access services. These barriers must be identified and addressed.

It is important that policymakers work toward inclusive cancer care provision through the introduction of public health campaigns that promote inclusive preventive services. Health professionals need to receive appropriate education and training regarding disability in order to dispel assumptions and negative attitudes.¹³ Listening to people with disabilities who have cancer is one of the most effective ways to change practice and create inclusive cancer services. Furthermore, better communication among various professionals and across different teams involved in a patient's care is paramount and can help raise awareness of how disability can interact with cancer-related care. At the same time, the creation of more accessible environments is crucial, including screening equipment such as that used for mammograms, and treatment processes such as radiotherapy.

As the population ages and an increasing number of people live with cancer and disability, ensuring that cancer services are disability-inclusive is more imperative than ever. Early and fast diagnosis, equity of access to treatment and care, and inclusive health promotion campaigns are key for the development of healthcare services that better respond to the needs of people with disabilities. Improving cancer outcomes is a complex endeavour that cannot be realized without the explicit consideration of people with disabilities and their participation in the decision-making processes.

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